



Help Lines  
for Rare  
Diseases

**EUROPEAN NETWORK  
OF RARE DISEASE HELP  
LINES**

**-MEMBERSHIP  
APPLICATION FORM-**

The following application form has been prepared by Eurordis with the input of rare disease help lines from across Europe. It is to be filled in and signed by any help line service wishing to become a member of the European Network of Rare Disease Help Lines. By applying to become a member you will be given feedback on your help line service and what tools exist to improve the quality of your service.

Once the application has been reviewed by the **Steering Committee**, the applicant help line will be notified about whether membership has been approved. The help line will be then offered an accredited membership and depending on the level of development a convergence plan will be drawn up highlighting where and how the service can be improved. The network will offer accreditation according to the level of development of the help line.

Please see the attached **APPLICATION FROM HANDBOOK** documentation for more information. If you have any questions please contact Shane Lynam, the Network Coordinator at Eurordis on 0033156535216 or [shane.lynam@eurordis.org](mailto:shane.lynam@eurordis.org).

## 1. Help Line Information

|   |   |                                      |                                  |
|---|---|--------------------------------------|----------------------------------|
| <b>1.1 Official Name of your Service</b>  |   |                                      |                                  |
| <b>1.2 Acronym</b>  |   | <b>1.3 Creation date</b>             |                                  |
| <b>1.4 Current Director</b>   |   |                                      |                                  |
| <b>1.5 Address</b>  |   |                                      |                                  |
| <b>1.6 Country</b>  |   |                                      |                                  |
| <b>1.7 Postal code</b>  |   | <b>1.8 City</b>                      |                                  |
| <b>1.9 Telephone</b>  |   | <b>1.10 Fax</b>                      |                                  |
| <b>1.11 e-mail</b>  |   | <b>1.12 Website</b>                  |                                  |
| <b>1.13 Contact person for ENRDHLS</b>  |   |                                      |                                  |
| <b>1.14 Contact e-mail</b>  |   | <b>1.15 Contact person telephone</b> |                                  |
| <b>1.16 Contact person Address</b> (if different from the main office)            |   |                                      |                                  |
| <b>1.17 Channels for enquiring</b>  | <b>Help Line Email address:</b>   | <input type="checkbox"/>             | <b>Help Line Website:</b>        |
|   | <b>Help Line Phone number :</b>   | <input type="checkbox"/>             | <b>Help Line Onsite visits :</b> |
|   | <b>Help Line Postal address:</b>  | <input type="checkbox"/>             |                                  |
| <b>1.18 Type of membership requested</b>  | Full Membership <input type="checkbox"/> <span style="margin-left: 200px;">Observer <input type="checkbox"/></span> |                                      |                                  |
| <b>1.19 Does your help line organise trainings/workshops? Please give details</b> |   |                                      |                                  |

|  |  |   |  |
|--|--|---|--|
| <p><b>1.20 Number of paid staff working at your help line?</b><br/> (Please indicate the profile of your staff, e.g psychologist, doctor, social worker..)</p> |  | <p><b>1.21 Number of volunteers working at your help line</b></p> |  |
| <p><b>1.22 What is the governance structure at your helpline?</b><br/> (please attach bylaws if available)</p>   |  |   |  |
| <p><b>1.23 Membership in other overarching organisations</b><br/> (please describe your level of autonomy in terms of decision making)</p>                     |  |   |  |
| <p><b>1.24 How is your help line/organisation financed,</b><br/> please indicate sources of financing in percentages?</p>                                      |  |   |  |
| <p><b>1.25 What is the cost structure for your phone calls?</b>(free calls, local call, flat rate or full rate)</p>  |  |   |  |

## 2 Technical information regarding your help line

**2.1 Is your service dealing with general or a specific group of diseases?**

**2.2 If it is a specific group of diseases please mention the name of the group and how many diseases this covers(if known)?**

**2.3 What languages are spoken by your help line respondents?**

**2.4 Number of calls emails/emails/letter/visits per annum?**  
Please include percentage where available

**2.5 Do you currently have a system in place to record the details of isolated patients?**

Please give details mentioning how many diseases and patients are in this list.

**2.5 Current call management database system in place**

(Please describe, leaving the details of the person directly responsible for this aspect at your organisation)

**2.6 Does your help line offer information or support on the following topics:**

- |  |  |
|--|--|
| Medical Information <input type="checkbox"/>   | Specialist centres <input type="checkbox"/>          |
| Social Care <input type="checkbox"/>           | Contact with other patients <input type="checkbox"/> |
| Follow-up <input type="checkbox"/>             | Legal questions <input type="checkbox"/>             |
| Social issues <input type="checkbox"/>         | Signposting <input type="checkbox"/>                 |
| Psychological support <input type="checkbox"/> | Association <input type="checkbox"/>                 |

|   |            |                          |
|---|------------|--------------------------|
| <p><b>2.7 Upon joining the network, your help line will:</b><br/> please tick if you will provide the item. (please see membership criteria in guide for help)</p>  |            | <input type="checkbox"/> |
| <p><b>1. Adopt the Orphanet disease coding system for all call management at your help line(If not already doing so)</b></p> <p>Please attach letter signed by Director or Board showing validation of this decision.</p>   | Comments:: |                          |
| <p><b>2. Ensure that your service is respecting local data privacy legislation</b></p> <p>Please attach document from lawyer or relevant authority.</p>   | Comments:  | <input type="checkbox"/> |
| <p><b>3. Participate in the Caller Profile Analysis by sharing information on number of calls, their genders, their relation to the patient, the purposes of the call, the diseases, the types of responses given.</b></p> <p>Please attach letter signed by Director or Board showing validation of this decision.</p> | Comments:  | <input type="checkbox"/> |
| <p><b>4. Agree to attend at least one workshop event every year</b></p> <p>Please attach letter signed by Director and Board showing validation of this decision</p>  | Comments:  | <input type="checkbox"/> |
| <p><b>5. Demonstrate the commitment of your management board</b></p>  | Comments:  | <input type="checkbox"/> |

**to support the network. Decisions should be taken on an independent basis and implemented as agreed.**

*Please attach letter signed by Director and Board showing validation of this decision*

I hereby declare that the information contained in the above application form to be accurate,

Name of Help Line Service

Signature of Organisation Director/Manager

Date

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